

Assistive technology service delivery for children with multiple disabilities : a family-centred approach to assure quality

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CHAPTER 8

Valorization of Research Results

The research project presented in this thesis describes the development of a framework to assure quality of the AT service delivery process, and to assess AT intervention outcome and the social cost associated to the provision of AT solutions for children with multiple disabilities. The framework for assuring ATSD quality, the methodologies developed and the knowledge gained regarding AT professionals' and parents' experience of the ATSD process may be considered the foundations to a more evidence-based AT provision in which quality of the entire ATSD process is continuously monitored and improved according to a family-centred approach. The results from this research project, in particular, may be relevant for a number of stakeholders.

Healthcare System

The research project described in this thesis has substantially contributed to integrating the CAT service activities within any possible Diagnostic Therapeutic Assistive Pathway (hereafter, PDTA) targeting children with complex health conditions and multiple disabilities as described in Chapter 7. Firstly, it formalized the CAT service procedures and methodologies to such a level of detail as to facilitate integration of the CAT activities within those of the other health professionals involved in the PDTA (see study Chapter 3). Secondly, since the quality of any PDTA – and of any service provided within a PDTA – is thus periodically evaluated, the quality assurance framework developed and described in Chapter 3 will serve as a standard in assessing ATSD quality and outcomes. Thirdly, the CAT model for AT documentation developed on the basis of the experience described in Chapter 4 may be used as an additional element for integrating the ATSD within the child's broader healthcare process. Integrated documentation is in fact a key strategy for enhancing multi-professional collaboration. The work of having established a clear set of essential dimensions and related information to be considered and collected for effective AT identification, selection, implementation and use may help AT professionals to co-ordinate their activities with those of other health professionals and to reduce the risk of developing conflicting goals within the rehabilitative/assistive intervention. The employment of ICT-based management systems for sharing such information would be helpful in improving the integration and coordination of the care process. The CAT model for AT documentation as developed in this thesis could be easily implemented in a digital format. However, the role of ICT in supporting management of the care process within the PDTA has only been theorized so far, and has still not been translated into practice due to a lack of technological resources and competences related to ICT and health. Lastly, estimation of costs associated to AT interventions may help in the process of evaluating the resources spent within the whole PDTA and, in turn, its overall efficiency.

Assistive Technology and Rehabilitation Professionals

Enabling quality comparisons of different ATSD systems is one of the main goals of the present research project. The results of this project as well as the methodology

employed may constitute the basis upon which AT professionals working in different Italian regions could develop strategies for collecting comparable information regarding the quality of their ATSD systems, starting from the measuring of the ATSD process and outcome. In this view, common instruments should be employed, and the results of this project have clearly shown that instruments already available for assessing AT intervention outcome could be used also with children.

The strategies proposed in this thesis may also be helpful in describing and measuring ATSD process quality. For example, the CAT service performed a two-day training course to update professionals working at the Montecatone Rehabilitation Institute, in the Imola local authority area (in the Emilia-Romagna region), to replicate the methodology developed in the study presented in Chapter 4. The scope was to develop clearer and more informative reports to support prescription of AT solutions for patients with spinal cord and traumatic brain injuries. Such an experience may be replicated, for example, with AT providers within the GLIC, the Italian association of independent AT centres described in Chapter 1.

Researchers

Further research is needed to refine the instruments employed in this research project and to advance knowledge regarding the quality of ATSD targeting children with multiple disabilities. The Italian version of the KWAZO scale to assess ATSD process outcome was adapted to the Italian context for the purposes of this thesis. Further research is already ongoing within the AT Area of the Corte Roncati Centre for Disabilities to evaluate the psychometric properties of this scale in relation to a larger sample of participants (children, adults, and elderly; $n=98$) who use different types of AT solutions.

In addition, AT professionals working at the CAT service have started to use the SCAI and IPPA tools at the end of any AT assessment. To facilitate data entry, a digital version of the SCAI tool has already been developed and included for the CAT users' database. Similarly, development of a digital version of the IPPA is currently ongoing. Through the systematic collection of information on AT intervention outcome, a clearer picture of the effects of AT solutions on the child's activities may emerge in the near future. After a first pilot-test conducted by professionals at the CAT, AT professionals working in different ATSD systems might also implement these tools in their daily practice.

Children and Their Families

This thesis clearly highlighted that children and their families should have a stronger role throughout the ATSD process. This is possible only by creating the conditions for increasing their involvement in the ATSD process in a manner that is feasible both for AT professionals and users. The focus-groups conducted for the purposes of this project and discussed in Chapter 5 were considered, both by AT professionals working at the CAT service and by some of the parents involved, as an experience worth repeating. In this view, focus-groups may be organized regularly to evaluate the AT service delivery

and to discuss any possible issue regarding the provision of AT solutions to children. People involved in the focus-groups may be users living in the Bologna local authority area, but also those from other areas within the Emilia Romagna region.

Furthermore, the creation of a repository where parents and teachers could share their experiences and materials (especially adapted books and other material related to augmentative and alternative communication) was suggested during one of the two focus-groups described in Chapter 5 to improve parent participation in AT intervention. The repository could be hosted by the CAT and managed by the CAT professionals together with the children's parents or, hopefully, by the children themselves.